

# The Caregiver

## Newsletter of the Duke Family Support Program

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Duke University Center for the Study  
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Alzheimer's Disease Research Center

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## NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

**Eastern NC Alzheimer's Association** – June 11<sup>th</sup> 2003 Support Group Facilitator Training – Chapter Office; October 4<sup>th</sup> 2003 – Memory Walk – Raleigh & Satellite Memory Walks; October 30<sup>th</sup> & 31<sup>st</sup> 2003—Annual Education Conference—Durham; Alzheimer's Care Training dates for families, community and professionals throughout Eastern NC. Call Chapter Office or access website for information.

**Western Carolina Chapter Alzheimer's Association**—Alzheimer's Disease/Dementia: Tips to Communicate Through Music: May 14-High Point; May 29 – Charlotte; June 10 -Asheville; June 24 – Hickory. May 22nd – Activity Based Alzheimer's Care: Building a Therapeutic Program, Statesville Civic Center, 300 South Center Street, Statesville, Registration, \$75 early bird discount, \$90 full registration (after May 15.) June 12, First Annual Memory Cup Charity Pro-Am, Carmel Country Club, Charlotte. 704-532-7395. Oct 7<sup>th</sup>, Third Annual Faith Hope, and Alzheimer's Disease Conference, Knollwood Baptist Church, Winston-Salem, NC; November 5, Alzheimer's Association Mountain Region Annual Caregiver Education Conference, Black Mountain. November 13<sup>th</sup>, Congregational outreach seminar, Hickory Grove Baptist Church, Charlotte—half day. Memory Walks are being scheduled for fall. Information: 704-532-7395.

**DIETARY FACTORS IN ALZHEIMER'S DISEASE:  
TRANSLATION TO PREVENTION AND TREATMENT****Donald E. Schmechel, M.D.**

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The basic model of Alzheimer's disease (AD) and related dementias is that the occurrence of disease in a given person is a complex interaction of genetic and environmental factors operating over long periods of time. Like hypertension, diabetes, and atherosclerosis, there are probable long periods of time where silent tissue injury occurs before clinical disease may present due to a catastrophic event or loss of final reserve. These long periods of silent and progressive tissue injury are influenced by genetic factors and environmental factors. The most common genetic risk factor is inheritance of one copy (25% of the population) or two copies (2% of the population) of the AD risk gene apolipoprotein E4. However, even the high risk E4/E4 persons (two copies) may vary in onset of clinical AD from age 48 to age 80+ or even escape altogether. There must be other environmental factors or other unknown genetic factors. Current research suggests that diet (an environmental factor) may be the major contributor to the rate of silent tissue injury during aging and age of onset of AD. The Western-style diet of industrialized nations is high in bad fats and cholesterol. The demand for fast food, prepared food, 'good tasting food', and big food portions has produced an epidemic of diabetes and obesity, and it is a factor for cancer, atherosclerosis, and now AD as well. At no time in history have so many people lived for so long consuming 'bad fuel' for their bodies. Our genetic background is not prepared for the combination of these extremes.

**DIETARY FACTORS: HIGH FAT AND CHOLESTEROL**

High levels of dietary fat and cholesterol increase AD pathology in transgenic mice models, in primate models and in preliminary studies in humans. More specifically, current evidence supports the specific effect of high cholesterol, saturated fats or trans fatty acids in generating this risk. In human epidemiological studies, consumption of saturated fat or trans fatty acid increases *incident* risk of AD by about two times after adjusting for all other factors like gender, age, education, and APOE genotype. Likewise, consumption of healthier fats (polyunsaturated fatty acids, omega-6 or omega-3 fatty acids) is associated with decreased risk of AD. For most people, this is equivalent to eating fish every week. Important studies in African-Americans and Nigerians have suggested that populations on traditional, agrarian diets have much reduced risk of AD (Hendrie et.al, 2001).

In animal studies, the risk difference related to type and amount of fat absorption appears to be significant. In a randomized controlled experiment of a high fat, high cholesterol (average American) diet in primates, only those animals on saturated fat diet with low HDL (good cholesterol) manifested AD pathology after five years of the diet (equivalent to humans on 20-30 years of diet). Although much work remains, this dietary effect may well be multi-factorial. Dietary factors may involve peripheral and brain metabolism and damage/injury repair to blood vessels. The modulating effect of HDL in primates would support the role of other genetic factors that affect lipid metabolism. Current trials with statins (drugs that lower cholesterol) are pharmaceutical ways of influencing the role of cholesterol and body lipids on AD risk. Important diet parameters may include: type of fat consumed, levels of good (HDL) and bad (LDL) cholesterol.

**The diet of many Americans is high in bad fats and cholesterol and constitutes a risk for AD that many be independent of APOE genetic risk factors, but related to genetic risk for low HDL levels. Many persons on American diets (60%) qualify for treatment of high cholesterol levels under current guidelines.**

**DIETARY FACTORS: IRON OVERLOAD**

Average American diets have iron supplementation in many prepared foods. Most persons have increasing body iron stores over time with men increasing from birth and most women blunted at low levels until after menopause (due to menstruation and childbirth). These levels approach 300-600 ppm of iron in liver (young persons with iron stores adequate for red cell formation average about 100-200 ppm). The average American diet is supplemented to roughly five to ten times more than the minimal daily requirement of 2 mg per day, primarily through addition of iron to bread, cereals and processed food. In addition, the combination of high fat, high cholesterol diets result in increased iron stores.

The common hemochromatosis gene (Hfe), which is usually clinically silent just like apolipoprotein E4, may be a genetic risk factor for AD. The Hfe effect may be to decrease age of onset by five years, a more modest effect than the APOE4 allele, which decreases age of onset by roughly ten years per allele. Like APOE4, the 'carrier' state or person with a single risk gene copy out of two possible is common: Hfe gene 10% of population are carriers of C282Y polymorphism; APOE gene, 20-30% of population are carriers of APOE4 polymorphism. This Hfe gene is associated with risk of dietary iron overload on common American diets and it is also affected by common hepatitis C infection (1% of population) and alcoholism.

Although the Hfe gene is a 'Caucasian' gene from Western Europe, many persons presenting with AD have abnormal indices of iron metabolism (roughly 40-50%) consistent with tendency to tissue overload and too much circulating free iron. Reducing iron intake to levels sufficient for red cell formation and/or getting rid of excess body iron by blood donation may be important factors in decreasing risk attributable to iron overload. CDC guidelines call for consideration of therapeutic phlebotomy for persons with serum ferritin levels of greater than 200 ng/ml at younger age ranges or with clinical disease.

**The diet of many Americans is high in iron and/or fat and this produces high body stores of iron and probably increased risk of AD.**

**DIETARY FACTORS: HOMOCYSTEINE LEVELS**

An important outcome of the Framingham Heart Study was the identification of increased plasma homocysteine levels as an eventual risk factor for AD. Homocysteine is a normal metabolite of liver and cellular metabolism involved in recycling of sulfur and high-energy compounds used by the body for synthesis. Vitamins such as folic acid (folate), vitamin B12 (cyanocobalamin), and vitamin B6 (pyridoxine) are cofactors for some of the enzymes affecting homocysteine metabolism. Low folic acid may contribute to elevations of homocysteine, which can damage blood vessels at higher levels. Folic acid replacement of 400 mcg to 2 mg per day can reverse these elevated levels in most cases (sometimes B6 and B12 supplements are also used). A very common polymorphism in the MTHFR gene (methylene tetrahydrofolate reductase enzyme) may contribute to higher levels of homocysteine. Recent papers have suggested that elevated homocysteine in patients presenting with apparent AD may be associated with white matter injury on MRI and a 'vascular' component to dementia even in the absence of clinically recognized stroke-like events. Thus, many cases of AD (up to 30-40%) may be accompanied by significant white matter disease or vascular dementia component. Elevated homocysteine may be one marker for this type of AD and is apparently preventable if identified and treated in the decades prior to AD onset. Trials are underway to understand the utility of treating this abnormality once the clinically evident part of the disease process has commenced.

**The diet of many Americans results in higher levels of homocysteine. The addition of folic acid (and sometimes B6 and B12) can control this risk for vascular injury and AD [Women in child-bearing age are already encouraged to supplement folic acid to reduce risk of birth defects].**

**DIETARY FACTORS: PLASMA THIAMINE, ALCOHOL, GLYCEMIC FOODS**

Intermediate metabolism may be a significant risk factor for vascular dementia and AD. Plasma thiamine levels and thiamine supply to the brain can be endangered classically by starvation, foods such as shelled rice without vitamin supplements, in diabetic persons with high blood sugars during a phase of insulin adjustment, or alcoholism. Glycemic foods (those foods high in simple carbohydrates) produce quick rises in blood sugar and insulin resistance over time. In addition, a number of persons not in the above categories come to Duke's Memory Disorders Clinic with low thiamine indices. Some of these people have mild gait ataxia, but lack the full symptoms of severe thiamine deficiency like confusion, ataxia, problems with eye movements, or heart failure. Our current practice is to supplement these persons with additional oral thiamine (vitamin b1) above MDA levels of 1.5 mg/day until a normal range of plasma thiamine levels are reached (usually 25-100 mg/day).

**SUMMARY: THE CHALLENGE OF LIFESTYLE CHANGES**

A number of dietary factors may affect risk of AD. These factors include dietary fat and cholesterol, particularly the bad fatty acids (saturated fat and trans-fatty acid), dietary iron overload, elevated homocysteine levels, and thiamine deficiency. All of these factors are independent sources of risk with some modulation by genetic factors (e.g., fat intake and HDL levels, dietary iron intake and Hfe gene). These dietary factors represent environmental risk of AD and vascular dementia whose modulation either before or during disease may alter disease risk and course of illness. Even with incompletely altered diet, dietary modification may decrease need for medication (e.g., lower dose of statins needed with dietary changes and exercise). **Environmental modification is possible through lifestyle changes, whereas genetic risk factors are not modifiable.**

**I. What is average American bad diet?**

- A. High in calories
- B. High in simple, refined carbohydrates (sugar, corn syrup, fructose)
- C. High in saturated fats and trans-fatty acid and low in fish/vegetables
- D. High in supplemented iron, other food additives and preservatives

**Issues:** Speed, convenience, social or emotional eating, larger portions

**Downside:** Crash diets to recover, production of diabetes, hyperinsulinism, metabolic syndrome or syndrome X, obesity, atherosclerosis and heart disease risk, increased cancer risk, subclinical inflammation, increased risk of AD (saturated or trans-fatty acids)

**Genetics vs. Environmental:** Even persons with potentially low genetic risk may be 'pushed' into AD on these diets; statins or similar drugs might counteract such bad diets.

**II. What are current directions for improving the American diet?**

- A. Reduction of calories – a variety of diets
- B. Increasing portions of fruits and vegetables – complex, non-glycemic carbohydrates
- C. Reduction of saturated fats and trans-fatty acids
- D. Increase intake of vegetables or fish high in unsaturated fatty acids, particularly omega-3
- E. Reduction of unneeded supplements such as iron (men), food additives, and preservatives

**Issues:** Slower food preparation, harder to eat out in restaurants, spoilage

**Downside:** Many potential diets, difficulties in sticking to a diet, dieting in face of pressure from social customs, friends and family.

**Genetics vs. Environmental:** Current evidence suggests that such diets will decrease incidence of AD and related disorders (e.g., vascular dementia) with relatively modest changes or alterations to diet; might result in decreased need for medications

**III. What types of diets might radically minimize risk of Alzheimer's disease?**

- A. Traditional diets: Okinawa Diet, Mediterranean Diet, basic regional diets using moderation and natural food stocks
- B. Reduction of saturated fat and trans-fatty acid intake – dramatically less intake of butter, marbled meats, hydrogenated vegetable oils, and pastries may decrease risk of AD. The risk for people with increased intake of these foods is roughly two times those of people on traditional diets.
- C. Reduction of Homocysteine – leafy vegetables, greens and folic acid supplementation. The risk for increased homocysteine to cause AD is roughly two times more for persons with high homocysteine levels.
- D. Increased use of fish oil or omega-3 in vegetables (e.g., flax seed) or supplements. The decreased risk for persons eating fish or using omega-3 supplements is roughly two times less than those who don't eat fish or use supplements.
- E. Caloric restriction; avoidance of simple carbohydrates – avoiding hyperinsulinism, syndrome X or metabolic syndrome, vascular risk

**Issues:** Same as **II.** on last page.

**Downside:** Same as **II.** on last page.

**Genetics vs. Environmental:** Relatively uncharted territory, may well markedly decrease incidence of AD and related disorders (e.g., vascular dementia) with significant changes or alterations to diet or reduced need for medications. Only persons at highest genetic risk *might* still be untouched by such dietary modifications and still need medication or therapy (for example, rare cases of genetic autosomal dominant AD or E4/4 persons with other environmental factors such as head injury).

**IV: WHAT'S GOOD FOR YOUR HEART IS GOOD FOR YOUR BRAIN**

**Basic Diet:** Discuss with your health care provider and your family.

**Key:** Can you stick to the diet over time? Can you afford it? Does it meet your specific health and medication needs?

**V. What about Supplements?**

- Multiple vitamin probably recommended as one ages
- Folate supplementation 400 mcg or more
- Thiamine supplementation (in my opinion, 25 mg or more)
- Total reduction of iron intake to no supplements after age 50 unless there is specific need (e.g., iron deficiency anemia)

**VI. Are there special recommendations for those at risk of dementia or stroke?**

- Use of antiplatelet agent such as coated aspirin 81-162 mg/day (check with physician)
- Fish oil supplement (omega-3) through reputable source or diet high in fatty fish
- Folate supplement at 1 mg/day or check of homocysteine level
- Thiamine replacement at 25 mg/day or check of thiamine level
- Vitamin E supplementation at 400 –1200 IU per day (probably 'healthy' diet low in saturated fats mitigates this need)

**References:**

[www.navigator.tufts.edu](http://www.navigator.tufts.edu) good source of nutritional information

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**SAVE THESE DATES**

**18<sup>th</sup> Annual Joseph and Kathleen Bryan  
Alzheimer's Disease Research Center  
Conference**

**February 12-13, 2004**

**Durham Marriott at the Civic Center  
Durham, NC**

Alzheimer's 2003: Advances and Challenges  
Scenes from the Conference  
February 13-14, 2003

Dr. Cornelia Beck cites evidence for non-pharmacological approaches to care.

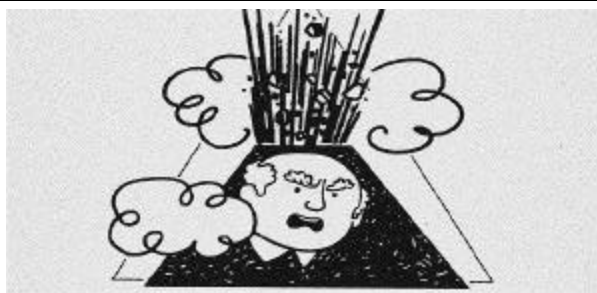
Dr. Jacobo Mintzer, a South Carolina geriatric psychiatrist, reminds nursing home staff to check for constipation as a trigger for behavioral changes.

Science comes alive under the microscope

Dr. Schmechel draws a picture in response to a question during informal discussion.

The "3 guys" presenters from 2002 conference return to greet friends.





**“WAIT A MINUTE!”  
When Anger Gets too Much**

**Wait a Minute!** “In the last few days even something little sets me off. I find myself yelling all the time. Then of course I end up feeling guilty. Poor Jim. He doesn’t deserve this.” **You may be exhausted. When you are rested and fit, you feel good about yourself, you’re more tolerant of common irritants, more accepting of annoying behaviors, and you tend to see more options for solving problems. Try to get some rest or a break from the caregiving routine.**

**Wait a Minute!** “Last night I actually broke three of my best wine goblets. I just needed to hit or break something. This morning I feel so foolish. I’m also mad at my husband. I know that’s unreasonable. Why do I *need* somebody to blame?” **Sometimes when we feel helpless or at a loss to control a situation, we feel better if we blame someone or something. You have a right to be angry at the situation but remember your husband is not the problem. Blame the disease. Healthy ways to express and work off anger: Go for a walk, bake or cook something that takes time and attention, call a friend, pray, clean a closet or whatever works for you.**

**Wait a Minute!** “More and more I feel empty inside, like I have no feelings, no pleasure in anything. I also have this fear that one day I am going to explode, and all these feelings are going to come from somewhere deep inside. It is frightening because I am afraid that something dreadful will happen.” **When we are running on empty, all emotions are dulled. We are just too tired to feel anything. It does not mean that anger, fear, and sadness are not there. Reach out. Get help. You can feel better. If family help is not available, look for paid services in your community.**

**Wait a Minute!** “There are things he does that set me off. ‘He’s doing this to spite me.’ I see them coming and yet, I respond the same way every time.” **Wait a minute. Count to ten before you respond. This really works. Maybe he needs reassurance, more structure (or less structure) a job or an activity that he can do without the expectation of perfection or standards that he can no longer attain, and appreciation for things he can still do. He also needs affection though it may be hard to be affectionate when you are mad. What are those things that always make you mad? Can these be changed in any way so they are less upsetting to you? The only option may be to change your attitude about these triggers.**

**Wait a Minute!** “I know that life is not fair but it still makes me so mad! Almost every day, I ask: ‘Why us?’ ‘Why her?’ And then there’s that awful answer from out of somewhere, ‘Why not you?’ ‘Why not her?’” **Alzheimer’s robs so much from the person who has it and from those who love and care for him or her. Keeping journals is one small way of responding: Write down all the good things you want to remember--some may be funny, some painful, some totally new information to other members of the family. In a separate journal write about the problems, losses, challenges, the anger and the triumphs of the caregiving journey. This may help maintain your perspective and sense of control. Families report that these journals become treasures later.**

**Wait a Minute!** “I am furious at the nursing home but I am afraid to say anything. If I have to move dad again, I don’t know what I’ll do. Today was the last straw. I walked in to see him and they had cut off all of his hair. It was as if someone had decided that this was one way not to have to give him another haircut. I wanted to cry. He was always so particular about his hair.” **Always speak up when there is a problem or concern about your family member’s care. The trick is knowing how. First, wait until you have calmed down, if you are angry. It may help to write down all of the issues to help you focus clearly. Focus only on the current concern, not everything that has been bothering you the whole year. Go to the right person first. If you are upset with the nursing assistant, talk first to him or her. Let her tell her side and LISTEN. You may be unaware of extenuating circumstances. If you are still not satisfied, talk to her supervisor, then the administrator, then the ombudsman—an ideal advocate for your family member. You may even want to start with the ombudsman if you are afraid of rocking the boat in the nursing home.**

**Wait a Minute!** “I am so tired of cleaning up behind him and everything else I have to do over and over and over. It’s never ending and I’m past the boiling point.” **Decide what’s worth doing and what you can give up. Delegate what you can and do only what’s necessary. Lower your standards. Get rid of everything you don’t use or need. Order brings a sense of control but should not be at the cost of drudgery.**

**Wait a Minute!** “I have to do everything myself. My mother has five children—my four brothers don’t think Mom has a problem. The only good thing about this disease is that she’s not aware of their terrible behavior. Their only concern seems to be whether or not I am spending her money frivolously on her care.” **You cannot make your brothers share in your mother’s care. You ask and then emotionally let it go when they refuse. You can only learn to make the job as easy for you as possible. For now, get a durable power-of-attorney for health care, and plan for facility care if that becomes necessary. Keep meticulous records of spending for her and show them to your brothers. Try a to-do calendar: taking Mom to the doctor one Tuesday a month, picking her up from the Adult Day Center at 3 p.m. each day. If she lives alone, assign maintenance chores such as cutting grass or picking up groceries. Let each of your brothers choose what he will be responsible for.**

**Wait a Minute!** “I’m trying. Nobody seems to appreciate that. My children and everybody just tell me what I’m doing wrong. Taking care of Amy is a full time job. Sure I’ve yelled at her a few times. Last night I shook her really hard. I took her to the toilet and when I went back to check on her she had made a mess everywhere except in the toilet. Like lightening I lost it. My kids talk psychology, but not one of them wipes butts. **All of us need information or help if we care. It’s not always easy even when you know HOW to do a job—to bathe the person, how to get her to eat, to use the toilet ..... The experts tell us that giving care is hard because we not only care for the person ( like helping with bathing or taking to the toilet) but we care about the person (like loving a wife and hurting when we see what’s happening to her). We forget that the first and maybe even the most important job is keeping ME, the caregiver, well so that anger doesn’t take over as easily when the going gets rough.**

**Wait a Minute!** “You tell me to take care of myself. How do I do that and what good would that do?” **Go to support groups where others in the same boat have good ideas. Take mini vacations even if they are planned, regular “daydream excursions.” Laugh. Get real breaks by actually getting away for a while. Think of your body as a machine and make a special effort to take care of it. It’s not unlike taking care of your car. How far would you get without gas or water in your car? Eat regular meals for the energy you need. Sleep to repair the wear and tear of the day. Exercise regularly—this is a great way to build strength and work off anger. Finally, learn to accept things that you cannot change. Learn how to triumph, even in small ways, despite what you can’t change.**

**Wait a Minute!** Write the name and number of one or two people you can call on to listen without giving advice or comment. Most people don't know how to just listen. Make a contract, explaining to your friend that you just need someone to listen and understand what you are going through at the moment. One wife called this her "bitching partner" –a woman she could call anytime when she needed to rant and rave and hang up once she calmed down.

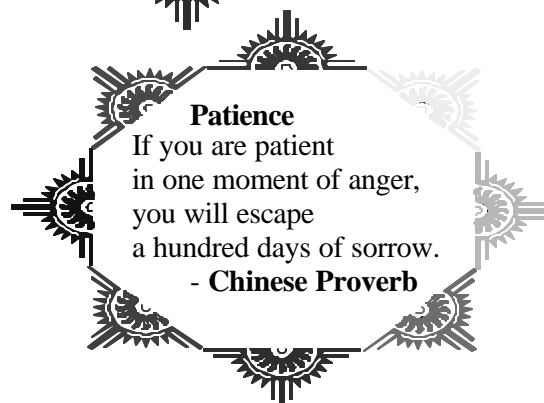
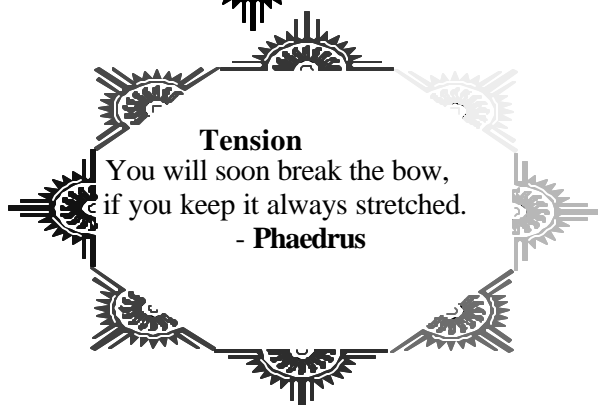
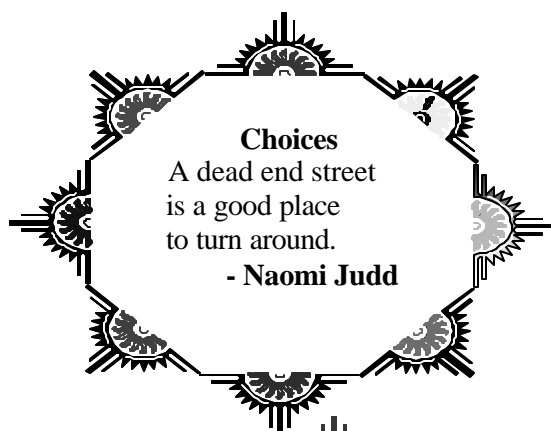
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**From the: Duke Family Support Program and the  
Joseph and Kathleen Bryan Alzheimer's Disease  
Research Center  
Box 3600 DUMC  
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Toll-free in NC ONLY: (800) 672-4213**

**Editor's Note:** "Wait a Minute!" is a draft of a 2003 two-sided, laminated refrigerator magnet for overwhelmed family caregivers. This new education/awareness product was developed for NC's Project C.A.R.E. (Caregiver Alternatives to Running on Empty), an Administration on Aging Alzheimer's Demonstration Grant. "Wait a Minute!" is adapted from Duke's popular book, Pressure Points: Alzheimer's and Anger (2000), available for \$8.00 pre-paid from Duke Family Support Program, 3600 DUMC, Durham, NC 27710.





## To Honor A Mother

### From a Daughter....

Was it through an open window flung wide to catch the first breath of spring?

Or

Was it through the door constantly swinging open and shut as only a door on a house with five children can?

Or

Was it down the chimney that wafted billowy smoke upward on chilly winter evenings?

How did the thief get in?

It really doesn't matter now, because he did.

He visited time and time again

Sneaking soundlessly into our house and stealing our treasure,

Taking a piece of you on each stealthy visit

Robbing you of your cognition, emotions, and memories

In essence, he stole your core.

I felt angry

cheated and robbed

How dare this thief steal you from me!

You were taken from me too soon.

You were gone before I was able to acknowledge your wisdom, strengths and gifts.

The thief committed his crimes before I was mature enough to appreciate all that you were.

I feel guilty.

I have lived with that guilt for a long time

But I am in a different place now

Our family was robbed

But not really

You were stolen

However, you do still exist

You exist in your children

I see you every day in my brothers, my sisters and in myself.

When I lend a hand to a neighbor

When I give a difficult person the benefit of the doubt

When I actively participate in the political process

When I find the strength in myself to get through one more difficult day

When I speak up for those who cannot find their voices

And

When I fight for equal rights for **ALL** people.

That is you, Mom

On one hand, you are gone

Yet, you still live on

You lit the fire in my soul with creativity, compassion, strength and fearlessness

And for that I thank you and I will love you forever.

Anonymous North Carolina Daughter

Submitted by a proud father

# Facts:

## About depression and Alzheimer's disease

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*Prepared by the Clinical Issues and Interventions Work Group of the Alzheimer's Association. February 10, 2003.*

Experts estimate that clinically significant depression occurs in about 20 to 40 percent of people with Alzheimer's disease. Individuals with Alzheimer's have the same right to adequate diagnosis and treatment of depression as any other person who develops the disorder.

Treatment of depression in Alzheimer's disease can improve sense of well-being, quality of life, and individual function, even in the presence of ongoing decline in memory and thinking. There are many potentially effective non-drug and drug therapies available and the benefits of treatment justify the cost.

### **Features of depression in Alzheimer's disease**

Identifying depression in Alzheimer's disease can be difficult. There is no single test or questionnaire to detect the condition and diagnosis requires careful evaluation of a variety of possible symptoms. Dementia itself can lead to certain symptoms commonly associated with depression, including apathy, loss of interest in activities and hobbies, and social withdrawal and isolation. The cognitive impairment experienced by people with Alzheimer's often makes it difficult for them to articulate their sadness, hopelessness, guilt, and other feelings associated with depression.

Although depression in Alzheimer's is often similar in its severity and duration to the disorder in people without dementia, in some cases it may be less severe, not last as long, or not recur as often. Depressive symptoms in Alzheimer's may come and go, in contrast to memory and thinking problems that worsen steadily over time. People with Alzheimer's and depression may be less likely to talk openly about wanting to kill themselves and they are less likely to attempt suicide than depressed individuals without dementia. Men and women with Alzheimer's experience depression with about equal frequency.

### **Diagnosis and proposed diagnostic criteria for "depression of Alzheimer's disease"**

The first step in diagnosis is a thorough professional evaluation. Side effects of medications or an unrecognized medical condition can sometimes produce symptoms of depression. Key elements of the evaluation will include a review of the person's medical history, a physical and mental examination, and interviews with family members who know the person well. Because of the complexities involved in diagnosing depression in someone with Alzheimer's, it may be helpful to consult a geriatric psychiatrist who specializes in recognizing and treating depression in older adults.

A group of investigators with extensive experience in studying and treating both late life

depression and dementia, working under the sponsorship of the U. S . National Institute of Mental Health, has proposed diagnostic criteria for a specific disorder called "depression of Alzheimer's disease." These criteria are designed to provide a consistent basis for research as well as to aid in identifying people with Alzheimer's who are also depressed. Although the criteria are similar to general diagnostic standards for major depression, they reduce emphasis on verbal expression and include irritability and social isolation. To meet these criteria, someone must have, in addition to an Alzheimer's diagnosis, a change in functioning characterized by three or more of the following symptoms during the same two-week period. The symptoms must include at least one of the first two on the list--depressed mood or decreased pleasure in usual activities.

- Significantly depressed mood--sad, hopeless, discouraged, tearful.
- Decreased positive feelings or reduced pleasure in response to social contacts and usual activities.
- Social isolation or withdrawal.
- Disruption in appetite that is not related to another medical condition.
- Disruption in sleep (a fact sheet about sleep changes in Alzheimer's disease is also available from the Alzheimer's Association).
- Agitation or slowed behavior (a fact sheet about agitation and Alzheimer's disease is also available from the Association).
- Irritability.
- Fatigue or loss of energy.
- Feelings of worthlessness or hopelessness, or inappropriate or excessive guilt.
- Recurrent thoughts of death, suicide plans, or a suicide attempt.

### **Treating depression in Alzheimer's disease**

The most common treatment for depression in Alzheimer's involves a combination of medicine, support, and gradual reconnection of the person to activities and people he or she finds pleasurable. Simply telling the person with Alzheimer's to "cheer up," "snap out of it," or "try harder" is seldom helpful. Depressed people with or without Alzheimer's are rarely able to make themselves better by sheer will or without lots of support, reassurance, and professional help. The following sections suggest non-drug strategies and medications that often prove helpful in treating depression in Alzheimer's.

### **Non-drug approaches**

- Schedule a predictable daily routine, taking advantage of the person's best time of day to undertake difficult tasks, such as bathing.
- Make a list of activities, people, or places that the person enjoys now and schedule these things more frequently.
- Help the person exercise regularly, particularly in the morning.
- Acknowledge the person's frustration or sadness, while continuing to express hope that he or she will feel better soon.
- Celebrate small successes and occasions.

- Find ways that the person can contribute to family life and be sure to recognize his or her contributions. At the same time, provide reassurance that the person is loved, respected, and appreciated as part of the family, and not just for what she or he can do now.
- Nurture the person with offers of favorite foods or soothing or inspirational activities.
- Reassure the person that he or she will not be abandoned.
- Consider supportive psychotherapy and/or a support group, especially an early-stage group for people with Alzheimer's who are aware of their diagnosis and prefer to take an active role in seeking help or helping others.

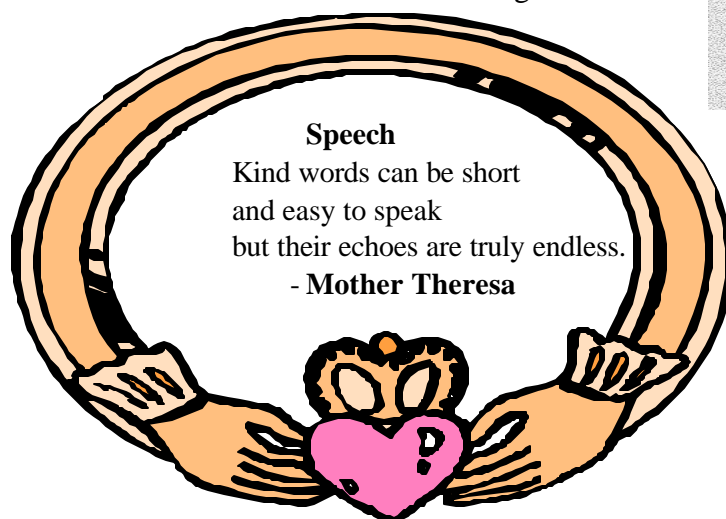
### Pharmaceutical approaches

Physicians often prescribe antidepressants for treatment of depressive symptoms in Alzheimer's. The most commonly used medications are in a class of drugs called selective serotonin reuptake inhibitors (SSRIs). These include citalopram (Celexa®), sertraline (Zoloft®), paroxetine (Paxil®) and fluoxetine (Prozac®). Physicians may also prescribe antidepressants that inhibit the reuptake of brain chemicals other than serotonin, including venlafaxine (sold as Effexor® and Effexor-SR®), mirtazapine (Remeron®) and bupropion (Wellbutrin®). Antidepressants in a class called the tricyclics, which includes nortriptyline (Pamelor®) and desipramine (Norpramine®), are no longer used as first-choice treatments, but are sometimes used when individuals do not benefit from other medications.

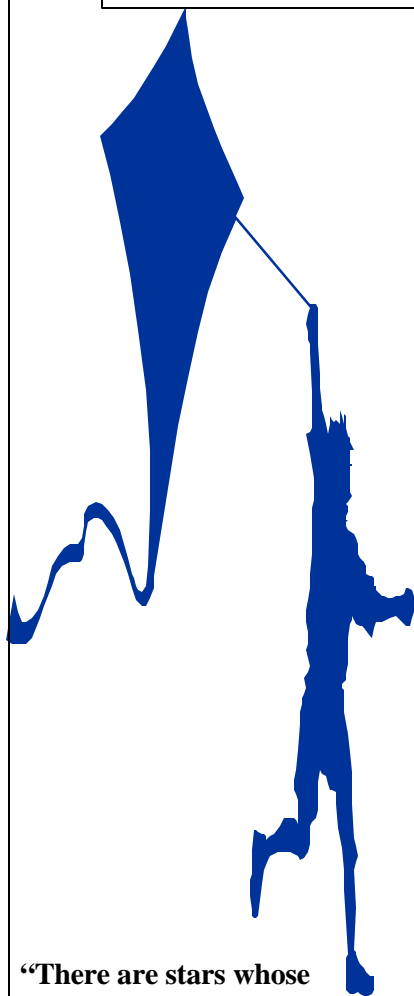
### Where can I get more information?

The proposed diagnostic criteria for "depression of Alzheimer's disease" are described in: Olin, J.T.; Schneider, L.S.; Katz, I.R.; et al. "Provisional Diagnostic Criteria for Depression of Alzheimer's Disease." *American Journal of Geriatric Psychiatry* 2002; 10: 125 - 128. On pages 129 - 141 following the article, there is a commentary by the authors discussing rationale and background for the criteria.

To request our fact sheets about sleep changes or agitation in Alzheimer's, or to speak with a call specialist or a professional care consultant regarding your other questions about dementia, please call our Contact Center at 800.272.3900. Our fact sheets and a wealth of other resources are also available on our Web site at [www.alz.org](http://www.alz.org).



At Rockaway Beach  
(Max Drucker, 1909-2003)  
Sally Ann Drucker  
New York



**“There are stars whose  
radiance is visible on earth,  
even though they have long  
been extinct...”**

Hannah Senesh, Holocaust poet

#### LOVE

We come to love  
not by finding the perfect person,  
but by learning to see  
an imperfect person  
perfectly.

- Sam Kenn



### Squinting

Sally Drucker

Once, numbered streets had names  
but remnants remain:  
a candy store, a diner  
the Van Alst train station  
retain their old sounds.

Brick walls of buildings  
show paint of lost ads  
some overlaid with new,  
all faded. Squinting,  
you see what used to be.

My father, ninety-three  
struggles to speak,  
words tangled on his tongue.  
He doesn't know names,  
just faces, smiles.  
Squinting, you see  
What used to be.







## Ahh, to Bridge the Gulf...

© Henry Walker  
Durham, NC—November, 2002

“Did she know you?”

“Do you know who this is? This is your son Henry. . . Don’t you remember?”

No matter how much we understand  
that Alzheimer’s steals names  
and short-circuits the wires  
that connect head and heart to tongue  
we still slip into using names and wanting the words,

I am gifted with how well  
my head and heart can connect  
and build words into bridges  
that can carry us over the gulfs that separate us  
from understanding the gifts revealed in  
a moment,  
an experience,  
another,

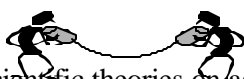
My gift with words  
opens me even more to the tragedy of Alzheimer’s  
when no matter how well I build my bridge from my side  
there’s no firm ground across the chasm I can reach,  
my heart can get across,  
and I have to shut up to words  
and just be there with Mother,  
smile to her eyes, kiss her cheek,  
**act to do so that she can be,**

when we are moved as deep as we can fathom  
we build what bridges we can without words:  
cakes and casseroles after a death or during an illness,  
a hug and a kiss on the cheek  
after being separated or after a wedding,  
a tear if we can let ourselves,  
a laugh when it’s just so right,  
or just so absurd,

and sometimes all that we can do is inside  
with no discernible bridge, no ready clue to others  
as to where our heart and head are taking us,

maybe Alzheimer’s can help us all grow larger in how we feel  
and larger in appreciating how varied the ways  
to span the gulf between us and all that’s out there.

## Have You Heard About?



Aging Under the Microscope. Current scientific theories on aging. National Institute on Aging. 800-222-2225 or email at [niaic@jbs1.com](mailto:niaic@jbs1.com). Included in the "Caregiver Kit" from ADEAR. 800-438-4380 or [www.alzheimers.org](http://www.alzheimers.org).

Braff, S & Glenik, MR. (2003) Staying Connected While Letting Go: The Paradox of Alzheimer's Caregiving. New York, NY: M Evans and Company. Hardback. \$21.95.

Caregiver kits. Spanish and English. Published by the ADEAR Center. [www.alzheimers.org](http://www.alzheimers.org) or call ADEAR at 1-800-438-4380.

Carr, S and Choron S. (2003). 1001 Tips for Caregivers: Experienced Caregivers Share Their Time-Tested Ideas and Advice. ISBN: 0071395199. Paperback. [www.amazon.com](http://www.amazon.com).

Coon, DW, Gallagher-Thompson, D and Thompson, LW (eds). (2003) Innovative Interventions to Reduce Dementia Caregiver Distress: A Clinical Guide. (See in-home intervention chapter by Gitlin & Gwyther) New York, NY: Springer Publishing Company. Hardback.

Cooney, EV. (2003) Death in Slow Motion: My Mother's Descent into Alzheimer's. ISBN: 0066213967. \$16.77. [www.amazon.com](http://www.amazon.com).

Coughlin, KM & Margolis, HS. (2002). Looking Ahead: Estate and Long-Term Care Planning For You and Your Family. Paperback. From [www.eldercareanswers.com](http://www.eldercareanswers.com), Address: 137 Newburg St., 2<sup>nd</sup> floor, Boston, MA 02116.

Ethnic Communities and Dementia: Making a Difference (2001). VHS 20 minute videotape. Highlights 4 model programs in Washington State. \$30.00. [haupthp@dshs.wa.gov](mailto:haupthp@dshs.wa.gov)

Horowitz, J, Faggella, K, Goldfein, S., Mathews, M. Conversations: An Activity Book for Making Connections with Older Adults. Ideas "R" Popping. (203) 221-7917, [www.ideasrpoping.com](http://www.ideasrpoping.com). \$8.95

Kakugawa, Frances H. et al. Mosaic Moon: Caregiving Through Poetry. Experiences of caregivers who attend a special Poetry and Journaling group in Hawaii. Watermark Publishing, 218 pages, [www.amazon.com](http://www.amazon.com), \$16.95.

Kuhn, D. (2003) Alzheimer's Early Stages. Second Edition. Available in paper and hardback. [www.amazon.com](http://www.amazon.com). Hunterhouse. [www.hunterhouse.com](http://www.hunterhouse.com).

Loss and Grieving Tips Brochure series (2002). Order free by sending email to [LastActs@aol.com](mailto:LastActs@aol.com), put "Tips Brochure" in subject line and include your name, street address, and phone.

McKann, G, & Albert, M. (2002) Keep Your Brain Young: The Complete Guide to Physical and Emotional Health and Longevity. John Wiley and Sons, Inc., 296 pp., John Wiley and Sons, Inc., 111 River St, Hoboken, NJ 07030, [www.wiley.com](http://www.wiley.com), \$24.95

Miller, MD & Reynolds, CF. (2002) Living Longer Depression Free: A Family Guide to Recognizing, Treating and Preventing Depression in Later Life. Baltimore: The Johns Hopkins University Press. ISBN#0-8018-6943-9. Paperback. [www.press.jhu.edu](http://www.press.jhu.edu), \$17.95

US Department of Health and Human Services, Public Health Service, NIH, NIA. Exercise: A Guide from the National Institute on Aging. NIH Publication No. 01-4258. [www.nih.gov/nia](http://www.nih.gov/nia). (800)222-2225.

## Websites to Watch



[www.ec-online.net/Knowledge/Articles/balance.html](http://www.ec-online.net/Knowledge/Articles/balance.html). Tips and exercises to improve balance.

[www.parkinson.org](http://www.parkinson.org). Information site for Parkinson's Disease

[www.elderweb.com](http://www.elderweb.com). Long term care information including database for organizations, articles, reports, news and events.

[www.healthycaregiver.com](http://www.healthycaregiver.com). Information and issues for adults caring for aging parents.

[http://research.aarp.org/health/inb54\\_inflation.html](http://research.aarp.org/health/inb54_inflation.html). AARP study on long term care policies.

[www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html](http://www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html). Great government site for AD families and professionals.

[www.mayoclinic.com/invoke.cfm?id=H000125](http://www.mayoclinic.com/invoke.cfm?id=H000125). Practical tips for Alzheimer's caregivers.

<http://alzinfo.org>. Foundation site worth watching.

<http://www.disabilityinfo.gov/>. Federal website of disability-related government resources.

<http://www.elderlawanswers.com>. Looking ahead – guide to estate planning. To find enter “Looking Ahead” in the “Search Our Site” block.

[www.strokeassociation.org](http://www.strokeassociation.org). American Stroke Association.

[www.strokenetwork.org](http://www.strokenetwork.org). Collection of websites for stroke survivors, family caregivers and health professionals.

[www.BenefitsCheckUpRx.com](http://www.BenefitsCheckUpRx.com). Eligibility for prescription savings for seniors.

<http://painaid.painfoundation.org>. Information on Pain in message boards and chat rooms; guest speakers; and Ask the Expert section.

[www.healthandage.com](http://www.healthandage.com). Look in the “Public” area, go to the “Depression” topic in the Health Centers. Open the article “Beating the Senior Blues” by Robert Griffith.

[www.fullcircleguard.com/caregiverissues/financial/payplanning.htm#insurance](http://www.fullcircleguard.com/caregiverissues/financial/payplanning.htm#insurance). Paying for care information.

[www.dhhs.state.nc.us/lrc/](http://www.dhhs.state.nc.us/lrc/). Long-term care website for the NC Dept. of Health and Human Services.

[www.dhhs.state.nc.us/aging/home.htm](http://www.dhhs.state.nc.us/aging/home.htm). NC Division of Aging website.

[www.ama-assn.org/ama/pub](http://www.ama-assn.org/ama/pub). Caregiver Self-Assessment Questionnaire. Free printed packet and free online.

[www.cargiving-solutions.com/index.html](http://www.cargiving-solutions.com/index.html). Alzheimer's solutions' tips.

[www.nchealth-info.org](http://www.nchealth-info.org). Health services in 100 NC counties.

[www.strokesafe.org](http://www.strokesafe.org). See stroke caregivers handbook.



**New!** [www.matherlifeways.com](http://www.matherlifeways.com). (See link to Caring with Confidence.) Newsletter based on Powerful Tools for Caregivers course (taught in NC by Dr. Luci Bearon and Edna Ballard, MSW). 12 month subscription discount before June 30, 2003. \$22.95. Toll-free (888) 722-6468.

### Serenity

There is more to life  
than increasing its speed.

-Gandhi

